

UNITED STATES DISTRICT COURT
WESTERN DISTRICT OF WASHINGTON
AT SEATTLE

DISABILITY RIGHTS WASHINGTON, a
nonprofit membership organization for the federally
mandated Protection and Advocacy Systems,

Plaintiff,

v.

TONIK JOSEPH, in her official capacity as Interim
Assistant Secretary for the Developmental
Disabilities Administration of the Washington
Department of Social & Health Services,

Defendant.

Case No. 23-1668

COMPLAINT FOR DECLARATORY
AND INJUNCTIVE RELIEF

I. INTRODUCTION

1. Plaintiff, Disability Rights Washington (“DRW”) is Washington’s designated, federally mandated, Protection and Advocacy agency (“P&A”); charged with the duty to ensure the protection of, and advocacy for, the legal and human rights of people with disabilities under the Developmental Disabilities Assistance and Bill of Rights (“DD Act”) of 2000, 42 U.S.C. § 15001 *et seq.*; the Protection and Advocacy for Individuals with Mental Illness (“PAIMI”) Act, 42 U.S.C. § 10801 *et seq.*; and the Protection and Advocacy for Individual Rights (“PAIR”)

1 Program of the Rehabilitation Act of 1973, 29 U.S.C. § 794e *et seq.* (collectively, the
2 “P&A Acts”)¹; *see also* RCW 71A.10.080.

3 2. DRW brings this action pursuant to 42 U.S.C. § 1983 and relevant provisions of
4 the DD Act.

5 3. Under the P&A Acts, DRW has the authority to “pursue legal,
6 administrative, and other appropriate remedies or approaches” to carry out its functions.
7 42 U.S.C. § 15043(a)(2)(A)(i).

8 4. The P&A Acts establish distinct functions of a P&A to include
9 investigation, education, and monitoring. *See Equip for Equal., Inc. v. Ingalls Mem'l*
10 *Hosp.*, 292 F. Supp. 2d 1086, 1094 (N.D. Ill. 2003).

11 5. Further, for a P&A to carry out its functions and meet the statutory
12 purpose of protecting the rights of such persons, the P&A Acts grant a P&A, such as
13 DRW, broad and unaccompanied access to people with developmental disabilities, in a
14 location in which services, supports, and other assistance are provided, including access
15 to records of service providers for individuals with disabilities. *See* 42 U.S.C § 15043
16 (a)(2)(H)); 45 C.F.R. § 1326.27.

17 6. This case involves DRW’s non-investigatory monitoring authority to
18 access information from the Developmental Disabilities Administration (DDA), of the
19 Washington Department of Social and Health Services, related to its implementation of a
20 modern community-based service called Remote Supports.

21
22 ¹ These statutes are to be read and construed *in pari materia*. *See Ala. Disabilities Advoc. Program v. J.S. Tarwater*
23 *Dev. Ctr.*, 894 F. Supp. 424, 428 (M.D. Ala. 1995), *aff’d*, 97 F.3d 492 (11th Cir. 1996); *see generally* 62 Fed. Reg.
53548, 53549 (Oct. 15, 1997) (noting Congressional intent that closely similar provisions of the DD Act and the
PAIMI Act were to be construed and applied in a consistent manner).

7. DDA has repeatedly denied DRW's authority to unaccompanied access to information regarding this service and of those who might be receiving or eligible for this service.

8. In recent years, many states have introduced Remote Supports in programs for individuals with developmental disabilities.² This service utilizes technology, such as motion sensors and two-way audio-video tools, to give instant access to trained staff for assistance. It aids individuals in daily tasks, promoting greater independence and offering caregivers event notifications, like home departures. Remote Supports not only has the potential to improve quality of life and autonomy but can also reduce the reliance on in-person staff, enabling individuals to remain in their homes or community settings.

9. According to DDA's website:

Remote Support provides supervision, coaching and consultation through technology devices installed in your home and through connection with your provider over video chat or similar technologies.

The contracted provider and the technologies must follow health information privacy laws and protect client privacy. Remote Support is available to DDA clients on the Individual and Family Services, Basic Plus and Core waivers. It is for clients who are not receiving residential habilitation.

See Developmental Disabilities Administration, Remote Support: A New Waiver Service From DDA, Informing Families, *available at* <https://informingfamilies.org/remote-support-dda/> (last visited October 29, 2023).

² Wagner, Jordan B., Marc J. Tasse, and Gili Ornan, *Implementation of remote support services: Pre-COVID-19*, J Policy Pract Intellect Disabil.2022;19:340–349, *available at* <https://onlinelibrary.wiley.com/doi/epdf/10.1111/jppi.12420> (last visited October, 19,2023)

10. Consistent with the DD Act mandates, DRW seeks to monitor how Remote Supports are administered to individuals with developmental disabilities in the state of Washington. This is to determine whether the service is being implemented in a way consistent with the rights, safety, and well-being of individuals with disabilities. *See* 45 CFR § 1326.27 (c)(2)(ii) (specifying a purpose of P&A monitoring access authority to “[m]onitoring compliance with respect to the rights and safety of individuals with developmental disabilities”).

11. DDA has impeded this effort by expressly denying DRW’s federal access authority and declining to adhere to federal regulations requiring disclosure to DRW of the contact information of DDA clients.

12. Without this access, DRW cannot effectively monitor the DDA’s provision of remote services, further shrouding the service against independent review.

13. This, in turn, heightens concerns for how DDA remote supports are impacting those with developmental disability.

14. Accordingly, DRW seeks to enforce its rights to access information and monitor DDA’s provision of remote supports.

II. PARTIES

15. ***Plaintiff Disability Rights Washington (DRW).*** DRW, a nonprofit corporation duly organized under the laws of the State of Washington, is the statewide protection and advocacy system designated by the Governor of the State of Washington to protect and advocate for the legal and civil rights of residents of this state who have disabilities, pursuant to the Protection and Advocacy for Individuals with Mental Illnesses (“PAIMI”) Act, 42 U.S.C. §§ 10801–51; the Protection and Advocacy for

Individual Rights (“PAIR”) Act, 29 U.S.C. § 794e; the Developmental Disabilities Assistance and Bill of Rights (“DD”) Act, 42 U.S.C. §§ 15041–45; and RCW 71A.10.080, collectively referred to as the P&A Acts. . Disability Rights Washington is federally funded and mandated to monitor settings and programs serving people with disabilities, conduct investigations of abuse and neglect of individuals with disabilities, provide individuals with technical assistance and information relating to their needs, and litigate on behalf of its constituents to enforce their rights. 29 U.S.C. § 794e(f)(3); 42 U.S.C. § 10805(a)(1)–(2); 42 U.S.C. § 15043(a)(2).

16. ***Defendant Tonik Joseph.*** Defendant Joseph is the Interim Secretary of DDA of the Department of Social and Health Services. DDA is responsible for implementing the Home and Community-Based services authorized under the Medicaid Act for individuals with developmental disabilities in Washington State. Defendant Joseph is responsible for the administration and operation of DDA. Defendant Joseph is sued in her official capacity only. All alleged acts or omissions by Defendant Joseph, were taken under color of state law.

III. JURISDICTION AND VENUE

17. DRW brings this action for declaratory and injunctive relief for violation of the DD Act 42 U.S.C. §§ 15001 *et seq.*

18. This Court has jurisdiction over this action pursuant to 28 U.S.C. §§ 1331 and 1343(a)(3) and (4), which grant this Court original jurisdiction in all actions authorized by 42 U.S.C. § 1983 to redress the deprivation under color of State law of any rights, privileges, or immunities guaranteed by the United States Constitution and Acts of Congress.

19. Venue is proper in this Court pursuant to 28 U.S.C. § 1391(b)(2), because all or a substantial part of Defendants’ acts and omissions giving rise to Plaintiff’s claims asserted in this action occurred within this judicial district.

20. This action seeks injunctive relief pursuant to Fed. R. Civ. P. 65, and declaratory relief pursuant to Fed. R. Civ. P. 57 and 28 U.S.C. §§ 2201-2202.

IV. BACKGROUND

A. P&A Access Authority

21. Under federal law, DRW has broad access to individuals and records to carry out its mandated activities. *See Alabama Disabilities Advocacy Program v. J.S. Tarwater Developmental Ctr.*, 97 F.3d 492, 497 (11th Cir. 1996) (“It is clear that the Act provides express authority for P&As to gain broad access to records, facilities, and residents to ensure that the Act’s mandates can be effectively pursued.”).

22. The U.S. Department of Health and Human Services (HHS) has promulgated implementing regulations of the DD Act, which also govern the access authority of any P&A system, including DRW. *See* 45 CFR § 1326.27 (a) (“Access to service providers and individuals with developmental disabilities shall be extended to all authorized agents of a P&A system.”).

23. Within CFR § 1326.27 (b), the regulation describes the authority of a P&A’s access for investigatory activities, while paragraph (c) applies to routine, non-investigatory, monitoring activities. 45 CFR § 1326.27 (c).

24. Under paragraph (c), “a P&A system shall have reasonable unaccompanied access to service providers for routine circumstances.” 45 CFR § 1326.27 (c); *see also Connecticut Office of Prot. & Advocacy For Persons With Disabilities v. Hartford Bd. of Educ.*, 464 F.3d 229, 242 (2d Cir. 2006) (“[T]he [DD Act] provides access to service recipients for both investigatory and monitoring purposes, i.e., to

investigate past instances of suspected abuse or neglect and to monitor to ensure current respect for the rights and safety of service recipients.”).

25. This paragraph further requires that:

Access to service providers shall be afforded immediately upon an oral or written request by the P&A system. Except where complying with the P&A's request would interfere with treatment or therapy to be provided, service providers shall provide access to individuals for the purpose covered by this paragraph.

Id.

26. Concomitant to this access authority is DRW's right to:

Unaccompanied access to individuals with developmental disabilities including, but not limited to, the opportunity to meet and communicate privately with individuals regularly, both formally and informally, by telephone, mail and in person. This authority shall also include the opportunity to meet, communicate with, or interview any individual with a developmental disability[.]

See id at (d).

27. In final rule guidance pertaining to the DD Act, the term “service providers” is meant to encompass a “broad range of entities currently providing services to be inclusively represented.” 80 Fed. Reg. 44796, 44800 (Aug. 26, 2015). This is because “[t]he DD Act is clear that P&As have access to people with developmental disabilities, in a location in which services, supports, and other assistance are provided.” 80 Fed. Reg. 44801 (quoting 42 U.S.C § 15043 (a)(2)(H))(citation and quotation marks omitted). The guidance further explains that the term “service provider” provides flexibility to evolve with systems of care providing services outside congregate settings, because “[n]ow an individual is more likely to be living in a small group home, in an adult supported living (foster) home, with his or her own family or family member, or independently in his or her own home.” *Id.* Additionally, HHS affirms that the P&A access

1 authority extends to a P&A's monitoring function, "allow[ing] for access in
2 circumstances beyond where there is a pre-existing substantial allegation of
3 wrongdoing." 80 Fed. Reg. 44804.

4 28. Finally, if a P&A system's records request is denied due to alleged lack of
5 authorization, the contact details of individuals with disabilities and their legal guardians
6 must be included in the response. *See* 45 C.F.R. § 1326.26 ("...the P & A system shall be
7 provided... with a written statement of reasons for the denial or delay. In the case of a
8 denial for alleged lack of authorization, the name, address and telephone number of
9 individuals with developmental disabilities and legal guardians, conservators, or other
10 legal representative will be included in the aforementioned response."). The plain
11 language of the statute provides that the contact information shall be provided "whether
12 or not the P & A has probable cause to suspect abuse or neglect, or has received a
13 complaint." *Id.* Essentially, P&A systems have rights to all records of disabled
14 individuals if given access authorization, if they've received a related complaint, or if
15 they suspect abuse or neglect. *See* 42 U.S.C. § 15043(a)(2)(I). However, to obtain basic
16 contact information linked to an access request, the P&A system doesn't need to provide
17 any justification. *See e.g., Disability Rts. Pennsylvania v. Sch. Dist. of Philadelphia*, 377
18 F. Supp. 3d 482, 486 (E.D. Pa. 2019).

19 29. In declining to provide DRW with contact information for DRW
20 constituents receiving DDA services, DDA chooses to disregard the P&A authorities that
21 mandate disclosure—undermining the intent and spirit of the DD Act and interfering with
22 DRW's ability to monitor services provided to individuals with disabilities. *See* 45 C.F.R.
23

§ 1326.21 (c) (proscribing states from interfering with a P&A's exercise of their authority).

B. DDA and its provision of Remote Support Services

30. DDA provides various services to its clients participating in their programming, which includes case management. *See* RCW 71A.12.310 (detailing DDA case manager duties and to meet in-person with clients where they live); WAC § 388-828-1080; WAC § 388-845-0955.

31. To receive Remote Supports, a DDA client must meet eligibility requirements and have a developmental disability. *See* DDA Remote Support Policy 4.28, Definitions, *Client*, p.2, available at <https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/policy/policy4.28.pdf> (last visited October, 31, 2023); WAC § 388-823-0015 (1).

32. DDA develops an assessment for their clients to identify the client's needs and services DDA will authorize in a service plan, including Remote Supports services. *See* WAC § 388-828-1080 ("Only DDA employees can administer the DDA assessment."); WAC § 388-828-8000 (detailing purpose of service plan).

33. DDA is responsible for authorizing the provision of Remote Supports from a contracted remote supports provider. WAC § 388-845-0955.

34. Further, DDA policy requires that the DDA case manager oversee other aspects of Remote Support such as verifying that the client have given informed consent for Remote Supports services; maintaining a record of the remote supports service plan; and maintaining records of provider service notes. DDA Policy, *supra*, 4.28 pp.5-8.

35. DDA, therefore, plays an integral role for the receipt and maintenance of Remote Supports to its clients with developmental disabilities, which DRW may monitor through its access authority.

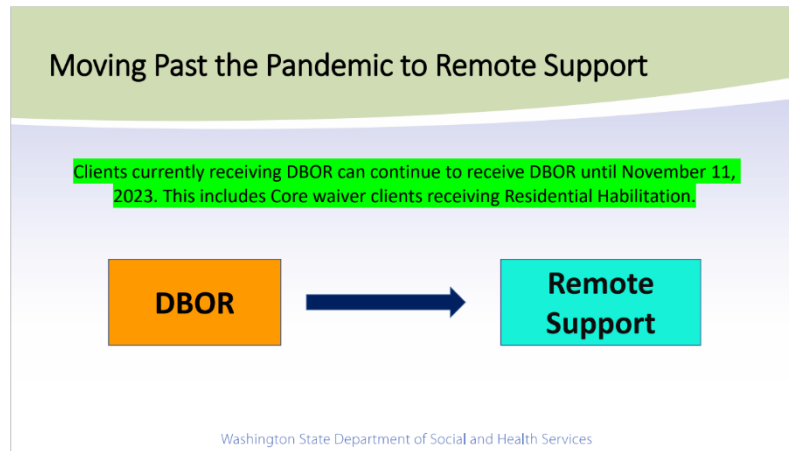
VII. FACTUAL ALLEGATIONS

1. DDA introduced Remote Supports, formerly known as Distanced Based Observation and Reporting (“DBOR”), during the COVID-19 pandemic. *See* Developmental Disabilities Administration, Remote Support: A New Waiver Service From DDA, Informing Families, *available* at <https://informingfamilies.org/remote-support-dda/> (last visited October 29, 2023). (“Remote Support is a new waiver service offered by DSHS’ Developmental Disabilities Administration. It is like Distance Based Observation and Reporting that was used during the COVID-19 pandemic.”); WAC § 388-845-2019(2)(g)(vii) (“Distance-based observation and reporting provided by an assistive technology distance-based observation and reporting specialist.”).

2. Upon information and belief, the service of Remote Supports is substantially the same as DBOR.

3. Upon information and belief, DDA began rebranding the service from DBOR to Remote Supports in 2022. *See* DDA Bulletin, *Assistive Technology and Distance-Based Observation and Reporting: Discussion and Feedback*, *available* at <https://content.govdelivery.com/accounts/WADSHSDDA/bulletins/3139f6a> (last visited October 31, 2023).

4. Upon information and belief, DDA trained its staff on the transition from DBOR to Remote Supports in a power point presentation, which was provided to DRW from DDA:



5. On October 10, 2023, DRW sent a letter to DDA, through its counsel Kathryn Krieger, requesting following for the period of January 1, 2021, to the present date of this letter:

a. The names, addresses, phone numbers, and email addresses of DDA participants, and of their guardians or legal representatives if applicable, who are currently receiving DDA remote supports;

b. The names, addresses, phone numbers, and email addresses of DDA participants, and of their guardians or legal representatives if applicable, who have requested DDA remote supports and were subsequently denied the service; and

c. The current participant capacity for DDA's remote services.³

6. In this letter, DRW provided DDA with DRW's statutory and regulatory authority to access this information under the DD Act, pursuant to DRW's monitoring authority.

³ See 42 U.S.C. § 15043 (a)(3)(B) (“[T]o the extent that information is available, the State shall provide to the system--information about the adequacy of health care and other services, supports, and assistance that individuals with developmental disabilities who are served through home and community-based waivers[.]”)

1 7. DRW, without waiving its authority, provided DDA a deadline of October
2 17, 2023.

3 8. Moreover, in the letter, DRW informed DDA, though its counsel, of their
4 obligation under 45 C.F.R. § 1326.26 to disclose the contact information of DDA participants
5 related to the request, should they decide to deny DRW's request.

6 9. DRW's letter indicated that should DDA fail to meet its obligations to
7 disclose the requested information, DRW may pursue litigation to redress the infraction.

8 10. On October 17, 2023, DDA responded to DRW's request denying access
9 to the information DRW sought and refusing to disclose the contact information for DDA
10 participants.

11 11. In their response, DDA represents and alleges that:

- 12 a. “DDA does not track who requested [Remote Supports], and
13 therefore DDA does not track who may have been denied the service[;]”
14 b. DDA does not know of a capacity limit for the service;
15 c. There have only been total of fifteen (15) participants from January 1,
16 2021, to October 10, 2023;
17 d. DRW lacks access authority because monitoring authority does not extend
18 to monitoring services received by individuals living in private homes;
19 e. DDA will not provide the contact information of DDA participants as
20 required under 45 C.F.R. § 1326.26; and
21 f. Instead of complying with the regulation, DDA will send a third-party
22 correspondence to DDA participants on behalf of DRW.
23

1 12. Prior to this, DRW had attempted to access important information regarding
2 Remote Support Services through DDA multiple times, and DDA has withheld the information
3 sought each time.

4 13. On July 12, 2022, DRW requested the contact information of service recipients,
5 or in the alternative, redacted Individual Instruction Service Plans (IISPs), Incident Reports, and
6 Weekly Reports within a three-month period.

7 14. On July 15, 2022, DDA denied DRW's request for contact information but
8 provided DRW with de-identified weekly reports, de-identified incident reports, and the contract
9 with the program service provider.

10 15. On July 28, 2023, DRW requested the following from the DDA:

- 11 a. Redacted Person-Centered Services Plans (PCSPs) for each DDA client on
12 the CORE waiver and Roads to Community Living (RCL) program that are
13 authorized to receive Remote Support services;
- 14 b. De-identified incident reports for any incidents related to Remote Supports,
15 with any incident reports correlated to the coinciding PCSPs since March 1,
16 2023; and
- 17 c. Alternatively, DRW requested contact information for these clients
18 including their name, telephone number, address, email, and guardian contact
19 information.

20 16. On August 4, 2023, DDA responded by denying DRW's request for contact
21 information and DDA merely offered "general information" about the program as well as to send
22 a third-party correspondence to the service recipients on behalf of DRW.
23

1 17. Because of DDA’s continual refusal to provide the information, DRW
2 must spend more time petitioning DDA to obtain information and less time pursuing its
3 function of monitoring the provision of Remote Supports—to advocate for and ensure the
4 human and legal rights of individuals with developmental disabilities.

5 18. DRW does not intend to use this contact information to initiate uninvited
6 home visits. Rather, DRW seeks to initiate communication, during regular business
7 hours, with the service recipient or their legal guardian to survey the information about
8 recipients' experience with DDA’s Remote Support services.

9 19. For the purposes of monitoring DDA Remote Support services, DRW
10 maintains its duty to respect individuals with developmental disabilities' privacy interests
11 and honor a recipient's request to terminate the communication. *See* 45 CFR §
12 1326.27(c)(2).

13 20. Additionally, while DDA represents in their October 17, 2023, denial that
14 there have only been fifteen (15) participants receiving remote supports since January 1,
15 2021, DDA previously represented there were a total of ninety-six (96) participants
16 receiving Remote Supports in fiscal year 2023 as of July 25, 2023. *See* Exhibit A,
17 attached, Email from DDA Program Manager (July 25, 2023)

18 21. This discrepancy in information raises serious concerns about the accuracy
19 of DDA’s record keeping and adequacy of availability of the service to meet the needs of
20 DDA participants—heightening the need for DRW to monitor the service with
21 unaccompanied access to DDA participants.

22. Further, the discrepancy of DDA's report on participant numbers calls into question whether DDA participants have been approved by DDA to receive Remote Supports and were subsequently denied this service by DDA.

VII. CAUSE OF ACTION—42 U.S.C. §1983

(The Developmental Disabilities Assistance and Bill of Rights (DD) Act of 2000 and 42 U.S.C. § 1983)

23. Plaintiff incorporates by reference and re-alleges the foregoing paragraphs of this Complaint as if fully set forth herein.

24. Defendant Joseph is charged with the administration and operation of DDA.

25. Defendant Joseph's complained-of acts and omissions were taken under color of, and pursuant to the authority granted to her, under state law.

26. Plaintiff has the authority to "pursue legal, administrative, and other appropriate remedies or approaches" to carry out its functions. 42 U.S.C. § 15043(a)(2)(A)(i).

27. The DD Act and its implementing regulations provide Plaintiff with the right to unaccompanied access to people with developmental disabilities, in a location in which services, supports, and other assistance are provided; including access to records of service providers for individuals with disabilities. *See* 42 U.S.C § 15043 (a)(2)(H)); 45 C.F.R. § 1326.27.

28. Defendant has refused and allowed DDA to refuse Plaintiffs requests for information pertaining to DDA's provision of Remote Supports to its beneficiaries who had developmental disabilities.

29. Defendant has refused and allowed DDA to refuse Plaintiff's right to contact information of DDA participants who are currently receiving DDA remote supports and of those

1 who have requested DDA remote supports and were subsequently denied the service,
2 contrary to 45 C.F.R. § 1326.26.

3 30. Accordingly, Defendant's acts and omissions set forth above have deprived
4 Plaintiff of rights under the DD Act.

5 31. Therefore, Plaintiff has a cause of action pursuant to 42 U.S.C. §1983,
6 because Defendant, acting under color of law, denied Plaintiff a federally protected right.

7 32. Plaintiff is entitled to declaratory relief under the Declaratory Judgment
8 Act, 28 U.S.C. §§ 2201- 2202.

9 33. Plaintiff is entitled to injunctive relief.

10 34. Plaintiff is entitled to recover its attorneys' fees, costs, and expenses in this
11 action pursuant to 42 U.S.C. §1988.

12 **VIII. REQUEST FOR RELIEF**

13 WHEREFORE, Plaintiff respectfully requests that this Court:

- 14 1. Declare in favor of Plaintiff, pursuant to 28 U.S.C. §§ 2201 and 2202, that
15 Defendant's refusal to provide the records DRW requested on October 10, 2023,
16 violates 42 U.S.C. § 1983;
- 17 2. Declare in favor of Plaintiff, in accordance with 28 U.S.C. § 2201, that
18 Defendants violated the DD Act, by refusing to provide DRW with the names and
19 contact information of DDA participants who are currently receiving DDA remote
20 supports and of those who have requested DDA remote supports and were
21 subsequently denied the service for the period of January 1, 2021, to October 10,
22 2023.

3. Declare that Defendants have an affirmative obligation to assure that the access rights granted to Plaintiff by the P&A Acts are fully and uniformly implemented within DDA;
4. Issue preliminary and permanent injunctive relief requiring Defendant to provide DRW with access to the requested records;
5. Issue preliminarily and permanent injunctive relief enjoining Defendant from violating Plaintiff's rights under the P&A Acts;
6. Award Plaintiff its reasonable attorneys' fees and costs pursuant to 42 U.S.C. § 1988; and
7. Award such other relief this as this Court deems just and proper.

DATED: November 1, 2023.

Respectfully Submitted,

DISABILITY RIGHTS WASHINGTON

/s/Sarah Eaton

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